Humanização hospitalar e violência simbólica: a percepção das mães em UTIs Neonatais.

Hospital humanization and symbolic violence: the perception of mothers in Neonatal ICUs.

Humanización hospitalaria y violencia simbólica: percepción de madres en las UCIs Neonatales.

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RESUMO: O artigo procura situar o processo de humanização no campo das relações de poder e analisa a ocorrência da violência simbólica como agravante da desumanização em hospitais. Para consecução do objetivo, foi realizada pesquisa qualitativa com mães cujos filhos estiveram internados em UTI Neonatal. A partir do resgate da história oral de vida os relatos foram tratados pelo método da Análise de discurso, sendo categorizados em fatores humanizadores e desumanizadores. Os relatos associados aos fatores humanizadores valorizaram o tratamento personalizado e não apenas de acordo com procedimentos técnicos. Quanto aos fatores desumanizadores, além da falta de estrutura física dos hospitais, emergem os relatos de não-acolhimento, de hostilidade e violência simbólica, evidenciando que o processo de humanização passa, sobretudo, pelo estabelecimento de relações menos assimétricas de poder entre a equipe hospitalar e as mães acompanhantes.
Palavras-chave: Política Nacional de Humanização. UTI Neonatal. História Oral de Vida. Violência Simbólica.

ABSTRACT: This paper aims at the humanization process in the field of power relations and analyzes the occurrence of symbolic violence as an aggravating dehumanization in hospitals. To achieve this objective, a qualitative study was conducted with mothers whose children were admitted to the NICU. From the rescue of oral history of life reports they were treated by the speech analysis method, being categorized in humanizing and dehumanizing factors. The reports associated with humanizing factors appreciated the personalized treatment and not only according to technical procedures. As for the dehumanizing factors, and the lack of physical structure of hospitals, emerging reports of non-acceptance, hostility, and symbolic violence, showing that the

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process of humanization implies, above all, the establishment of less asymmetrical power relations between hospital staff and accompanying mothers.

Keywords: National Humanization Policy. Neonatal ICU. Oral History of Life. Symbolic violence.

RESUMEN: Este trabajo tiene como objetivo localizar el proceso de humanización en el campo de las relaciones de poder y analiza la incidencia de la violencia simbólica como una deshumanización agravante en los hospitales. Para lograr el objetivo, la investigación cualitativa se llevó a cabo con las madres cuyos niños fueron ingresados en la UCIN. Desde el rescate de la historia oral de los informes de vida analizados a través del método de análisis del discurso, se categorizaron a los factores en humanización y deshumanización. Los relatos vinculados a factores de humanización apreciaron el tratamiento personalizado y no solo los procedimientos técnicos. En cuanto a los factores deshumanizantes, y la falta de estructura física de los hospitales, se relatan la no aceptación, hostilidad y violencia simbólica, que demuestran que el proceso de humanización implica, sobre todo, el establecimiento de relaciones de poder menos asimétricas entre el personal del hospital y las madres.

Palabras clave: política nacional de humanización; UCIN; historia oral de vida; violencia simbólica.

INTRODUCTION

Humanization in healthcare is gaining space in the academic debates and in the public policies. It reflects the need to reorient the relationship between the hospital and the patient, and still assumes that this is a socially-built up process. Thus, the importance of sharing the aspirations and expectations, experiences and alternatives, is fundamental to the humanization process in hospital care, especially in moments of physical, mental, and emotional vulnerability of the patient and the family.

Deslandes (2004)[1] strengthens the understanding of humanization sense as opposed to violence, whether it is an explicit or symbolic form. The explicit forms cover situations in which they are more easily visible and can be more-clearly identified, allowing for adopting measures for their resolution. However, there are still persistent forms of symbolic violence expressed in the hospital practice and which are more difficult to be recognized and, therefore, faced or prevented.

The introduction of new preventive, diagnostic, and therapeutic capabilities, in the medical area, made possible significant increase in survival of premature infants, each time smaller and/or with more severe co-morbidities[2], but also led to the submission of newborns to invasive treatments with high number of exams and procedures.

With the baby in the Neonatal ICU, the family goes from a protagonist status to a coadjutant status in providing cares to the baby. Touch, cuddle, change diaper, or any other type of care is done by the health professionals or under their supervision. The family is so under the power exercised by professionals working in the sector. The relationship that is established, in principle, is that of

a high specialized scientific knowledge and a widespread ignorance about the hospital practices, prognostics, reports, bureaucracy, technical terms, anyway, all hospital institutional apparatus to safeguard the patient's life. In this perspective, ICU's scenario can represent certain hostility relative to the neonate and the family, for its artificial lighting, low temperature, and high-tech equipment. In these units, although the primary objective of the team is to save lives, cares are patient-centered, consequently, there is little emphasis on emotional support to the family[3].

After birth, the neonate needing immediate support, either on grounds of prematurity or due to their clinical health conditions, is submitted to numerous invasive procedures that prioritize their survival outside the uterus, but also removes them from the mother's cherish. This removal can occur be few days or months, representing a sudden change in family life, since most of the time the mother is accompanying the child during hospitalization and is separated from the other members of the family[4].

ICU mothers, involved emotionally with their children, hospitalized and in need for intensive cares, are, most of the time, the people who are more vulnerable to a variety of emotional and psychological responsibilities for the family that are often expressed by states of shock, anxiety, anger, guilt, despair and fear[5]. regarding the user of healthcare services as an autonomous and worthy being is seen as a fundamental condition in a humanization process [6]. This assertive assumes to know who is this "other", their expectations, and their demands and provide mechanisms for promoting the free expression of these users, facilitating the verbalization of their actual demands.

This article is part of the Master's degree dissertation: Oral history of Mothers in a Neonatal ICU - rethinking the National Humanization Policy (Research approved by the Ethics Committee. CAAE number 322691140000005142), and aims to situate the humanization process in the field of power relations and emphasize how the occurrence of symbolic violence is a worsening of dehumanization in hospitals.

Humanization, power, and symbolic violence

The humanization, for Deslandes (2006)[7] and Ayres (2005)[8] is a polissemic concept that refers to reflections and propositions about new ways to act, establishing more symmetrical relationships between subjects, whereby the formal and scientific knowledge, the experiences and knowledge of patients and companions contribute for producing knowledge.

Such a concept sheds light on the problem of asymmetric relations between the subjects. In this way, there is a need to understand the humanization being also power relationships. The Neonatal ICUs, for example, it is possible to observe the existence of asymmetric power relationships, in which mothers, most often, have little information or knowledge about hospital practice. On the other hand, the whole medical team has very specific scientific and technical knowledge.

Foucault (1979)[9], says that power is something that is practiced, is effected and spreads

throughout the social structure.

The power is not justified entirely when one looks to characterize it for its repressive function. What interests you basically is not to expel men from social life, prevent the exercise of their activities, but rather manage the lives of men, control them on their actions, so that it may be possible and feasible to use them to the fullest, taking advantage of their potential and using a system of gradual and continuous improvement for their capabilities. Such objective is at the same time economic and political: increasing the effect of their work, that is, make men a work force, giving them a maximum economic utility; decrease their ability to revolt, strength, struggle, insurrection against the orders of power, neutralizing the effects of counter power, that is, make men docile politically [10].

The power is characterized by Foucault (1979)[9] as a social practice, historically constituted, found in any level of the social scale and can be viewed subtly or expressly, in the healthcare services. In the various processes that involve everyday activities at the hospital, the know-power relationships are present and permeate all spaces, generating asymmetric relationships between the different actors involved in searching space domains, competitiveness, and conflicts.

For Deslandes (2004)[1], the disrespect to the word of the patients, lack of information exchange between patient - healthcare professional, the weakness relative to listening and dialogue are examples that generate asymmetric relationships between patient - healthcare professional and compromise the quality of care provided by the healthcare professionals.

Foucault (1996)[11], in "The order of the speech", deals with the relationship between speech and power. For the author, there are diverse forms for speech control or exclusion. The forms for external speech control, are called by Foucault as deletion systems. For Foucault (1996)[11], three are three speech deletion systems: interdictions, opposition between reason and madness, and will of truth.

These forms of exclusion exert on the individuals some "kind of pressure", preventing or causing them to be afraid to announce the speech. Therefore, speech is designed as a form for domination of an individual on the other[11]. An example is the medical speech when using a technical language that is incomprehensible to the patients.

The humanization in Neonatal ICUs and power relationships established in this environment show some peculiarities opposite the hospital humanization in general, because the baby has no conditions to decide for themselves and, therefore, will be needing the monitoring of the mother, or of another responsible person, for making decisions and be co-responsible for the hospital's actions (or the medical staff).

This unequal relationship between patients/families and the hospital teams approaches the design of Bordieu (2007)[12], for which the symbolic power is defined by means of certain relations

between those who wield the power and those who are subject to it. For the author, what makes the power of words and the words of order, power to be able to maintain order or subverting it, is the belief in the legitimacy of the words and the one pronouncing them.

The symbolic power in the healthcare field, according to Pereira (2004)[13], is structured on pillars, as maintaining an almost absolute monopoly of knowledge on the body and the different ways to intervene in it, and the disqualification of the other while being a bearer of knowledge and rights over their own body and on the health.

Humanization and public policies

According to Deslandes (2004)[1], the term "humanization" is used for decades in the health field.

The initiatives identified with the humanization of childbirth and with the reproductive rights of women has been for decades, taking part in the feminist health movements. In turn, the humanization of assistance to children is part of a scope that is more targeted to low-weight babies, admitted to an ICU. Some healthcare models based on this principle, such as the Safe Motherhood and the Kangaroo Method projects, are widely supported by the Ministry of Health and by the World Health Organization, and considered reference for the pública1 network [1].

However, it was not until the year 2000, that the Ministry of Health, through the regulation of the National Program for Hospital Care Humanization (NPHCH) conferred legitimacy to the theme, with the inclusion of humanization in the agenda of the eleventh National Health Conference, held on December, the same year. The primary goal of the NPHCH was to improve relationships between professionals, between professionals/users and between hospital and community, with a view to improving the quality and effectiveness of the services provided in the hospitals [14]. In 2003, the NPHCH was replaced by the National Humanization Policy (NHP), constituting as a care policy that operates in all SUS network, no longer a specific program.

NHP was established still in 2003, having as guiding principles: the subjective and social dimension valorization in all the care and management practices in SUS, strengthening the commitment to the citizen's rights, emphasizing the respect to issues of gender, ethnicity, race, sexual orientation and specific populations (Indians, quilombo residents, riverains, settlers, etc.); strengthening of multidisciplinary teamwork, fostering the transversality and the grouping; support for building up cooperative and supportive networks, committed to health production and to the production of subjects; construction of autonomy and protagonism of subjects and collectives involved in SUS network; co-responsibility of those subjects in the management and care processes; strengthening social control with participatory nature in all SUS managing instances; commitment to the democratization of labor relations and valorization of healthcare professionals by stimulating permanent education processes[15].

NPH has some guiding principles that should serve as the basis for changes in the relationship

between professionals and users: welcome, autonomy, protagonism, and co-responsibility. It is a policy that puts in question health practices, built up based on the biomedical model, main epistemological referential to the training of field professionals[15].

Welcome involves observing and listening intently, able to perceive the various demands. As a guiding NPH concept, it may be understood as a principle aimed at a reflection of healthcare practices, because it recognizes the others in their differences from a commitment to accountability in the therapeutic meeting. In addition, NPH takes it also as a provision that operates concrete changes in work processes and in service management [16].

In the daily life of an infirmary, a broad set of factors involves professionals, patients, and companions. Consider these networks of relationships that involve the subjects and the values that permeate them is one of the reflections that impact in building up a shared accountability and allowing to understand that the human being is a being dependent on their networks, and these are, therefore, important to their health[16].

Autonomy refers to the decision-making capacity of the actors based on information, dialogue and enhancing the network of relationships that permeate the individuals. Is a value that is relative and inseparable from the dependency between the subjects. To fortify their autonomy requires incentive to the network of relationships that sustain them[17].

According to Alves, Deslandes and Mitre (2009)[16], this exercise of autonomy is directly related to the quality of information provided during the therapeutic meeting, because to the extent that the patient and companions provide and understand the context in which they are inserted, the autonomy of both may be more-fully exercised. Sharing necessary information involving the treatment allows us to establish a constructive participation in the therapeutic process, making possible for the subjects to manifest their protagonist capacity.   In this sense, welcome as a basic principle and allowing the construction of more dialogical relationships, may facilitate production of linkages, understanding the user as able to exercise their autonomy and their protagonist capacity, sharing responsibility for the care [16].

Benevides and Passos (2005)[18], claim that despite being considered an undeniable advance, the existence of National Humanization Policy with respect to NPHCH, these principles are still found in fragmented actions.

Humanization, expressed in fragmented actions and a vagueness and weakness of the concept, sees its senses linked to voluntarism, assistentialism, paternalism or even the technicality of a sustainable management in the administrative rationality and in the total quality[19].

Currently, humanization in Brazil is an object of laws, curriculum guidelines, and indicative of quality control in clinics and hospitals, besides the formation of Humanization Commissions and training of professionals in humanization [20]. However, the mere existence of the NHP, does

not automatically promotes structural changes in the biomedical rationale. As Lacerda and Valla (2003)[21] point out, the quality of doctor-patient relationship is critical for healthcare. The quality of the linkages, the satisfaction during the process and established communication are key elements.

According to Barra et al (2005)[22], the patient has three types of needs during their hospitalization: emotional comfort, physical comfort, and professional commitment, with humanized carte. However, the complexity of the intensive routine and the technological domain that reins in the individual actions, hinders the humanization process; in so far as it contributes to the standardization of the actions, in detriment of the individualized care, as advocated in the NPH (2003)[15].

The individualized care is described in the NPH (2003)[15] as the subjective dimension and collective valorization in all the care and management practices in SUS, strengthening the commitment with the rights of citizenship, highlighting the specific needs of gender, racial-ethnic orientation/sexual expression and specific segments[23], as, it is in the research's case, for mothers that are accompanying babies in Neonatal ICU.

1.   Humanization as a research object: Some methodological notes

Humanization as a research subject can contemplate diverse perspectives and each one may reveal the complexity and subjectivity involved in their contexts. However, it is important to note the perspective of those who suffer from what is considered as 'dehumanized' care.

In order to allow mothers that are accompanying babies admitted to NICU (Neonatal Intensive Care Unit), to made public their questions, criticisms, compliments and praises about the humanization in the ICU's everyday life, a research was conducted with six mothers, being three from a public hospital and three from a private hospital, who have had children previously admitted to NICU and who participated in actions of a certain Non-Governmental Organization, specializing in accommodation of mothers with children admitted to NICU, which brokered the contact with the same ones.

The division into two groups, public hospital and private hospital, was used because of the very composition of SUS, in the current hospital sector. According to La Forgia and Couttolenc (2008)[24], Brazil has a highly pluralistic hospital system, consisting of a range of organizational and financial arrangements that cover both the public as well as the private sector. All private hospitals involved in the research also have vacancies intended for SUS and are therefore subject to NHP standards (2003).

A qualitative research approach was used in order to reach the proposed objective.

According to Minayo (1992)[25], qualitative research works with subjective data, beliefs, values, opinions, phenomena, habits. In addition, according to the author, qualitative research is concerned, in the social sciences, with a level of reality that cannot be quantified, that is, it works with the

universe of meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of the relations in the processes and phenomena that cannot be reduced to the operationalization of variables [24].

For building up ICU mothers' narratives, one appealed to the Oral Life History, by giving priority to talk of the subjects who participated in or witnessed events, valuing the individual trajectory and experience of those involved in the research.

All interviews were undirected (no direct interference on the part of the researcher), and previously appointed by email or phone, and taking place in a place defined by the collaborators. The purpose of the study, information on the interview's recording, reading and signing the Free and Clarified Consent Form (FCCF) have been carried out before starting the interviews. All mothers had the option to remain anonymous and/or with the name and/or surname of their children in secrecy, as well as the hospital where they were admitted. Most mothers decided not to reveal the name of the institution to which they were referring to during the interview, not even to the researcher, it was not possible to analyze the characteristics of the same one. The interviews were analyzed using content analysis technique, as proposed by Bardin (1977)[26].

For Content Analysis, the used analysis categories were prepared at two different times. First time, analysis categories were elaborated on the basis of the guidelines of the National Humanization Policy[15], about factors that contribute to mitigate or aggravate the suffering of mothers that are accompanying babies admitted to Neonatal ICUs, emerging from two categories – grouped into humanizing factors and dehumanizing factors (Table 01).

Second time, after completing the interviews and the corpus of analysis, the need for creating subcategories was found, which would allow for a more detailed analysis. This procedure of elaborating corpus-based categories, taking into account the specificities of the corpus itself and the needs of the survey, is provided by the content analysis methodology[26].

In the "humanizing factors" category there were reports of situations where mothers have highlighted/valued the received care according to their specific characteristics and not just according to protocols; reports of situations where health professionals welcome the family, since the arrival of the baby in the ICU, informing the parents on all the steps of the treatments to which their children would be submitted; and situations in which the rights of the child were respected as advocated by the Statute of the Child and the Adolescent [29], as regards to the right to have a full-time companion for the hospitalized child and adolescent; being grouped in three subcategories: "individualized care", "welcome", and "respect for the rights of the child".

As dehumanizing factors, reference Deslandes approach (2006)[7] was used, which considers dehumanization as "the way to treat people as if they had less value and provide care below the standard, object for the same hierarchy process and social discrimination, found in healthcare

systems"[7].

The place and the words: delimitations of spaces and speeches in the construction of dehumanizing factors

The most emblematic cases of symbolic violence that appeared in the reports refer to decisions taken by medical teams without being shared with the mothers. In these cases, there was no welcome of families, where decisions are taken as a whole, after due information and clarifications about clinical procedures that will be carried out in the patients.

For Machado (1979)[30], the non-acceptance of the families is strategic for maintaining medical power in the institution, since knowledge constitute as a necessary element for power relationships and that the dialogue between health professional and user, becomes a political provision in the disputes for strength and domination.

The reports below demonstrate this power relationship that passes over the professional knowledge and mother's autonomy for child-related decisions. It is necessary to emphasize that no procedure cited by mothers was conducted in emergency situation, where there is no time for previous discussions.

I speak thus: [...] we see that EVERYTHING was done without our permission! I got there, they told me: "we did tracheotomy because he was going to atrophy". They did not ask: "do you want"? "We did the gastro because he was aspirating". They did not talk like this: "hi, we have other options[...]". They gave me the deal all set! Every time I got there, there was a novelty and I had to be prepared! (M2L254)

In addition, reports have emerged with technical information which it was not possible to be recognized by the mothers. This fact contributes to strengthening the asymmetry of power in the relationship between patient's mother and healthcare professional.

Then I questioned too much and then I was told: no, but in the discharge summary there is an acronym, saying HIC 2, which is an intracranial hemorrhage with 2 degree". But for me it means NOTHING! (Laughs) HIC 2 for me does not mean [...] anything! If you do not speak to me clearly, I do not belong to the medical area! (M4L672)

This authority relationship of the healthcare professional, where power asymmetry of the healthcare professional and the patient's mother is clear, was also noticeable in cases of death concerning the neonate, where by determination of the healthcare team that was in charge of the case, the mother had no opportunity to say good-bye to the son.

And then when they called from the hospital for me to go, she had already died and until I got the news, they wake me up, it took me two hours to arrive at the hospital. And when I arrived there they had already taken, they took her from the hospital and brought to the institute of forensic medicine, in such a way that I haven't seen this. I left the hospital, she was alive, and I have never seen her again, because the coffin was sealed. (M4L564)

According to Oliveira and Maruyama (2009)[31], when it comes to who has the clinical knowledge, namely, the healthcare professional, this one uses this tool in order to maintain their higher position in the professional-user relationship within the ICU ambience. Individuals who need healthcare service, for themselves or others, are subject to the rules and conduct of the professionals. This reality does not demand the use of physical violence, since that the power is exercised primarily by the purely symbolic paths of communication and knowledge, so that no one can question the legitimacy of the exercised power.

Humanizing factors: Breach of protocol and recognizing the role and function of mothers

If, at first time, the factors considered to be dehumanizing had a strong relation to team's behaviors that show some kind of symbolic violence; reports of behaviors that contribute to the humanization process emerged in the humanizing factors. In this case, what caught attention was the valorization of situations where there was a breach of protocol. Mothers have highlighted situations where the relationship of health professionals was not merely protocol-bases, but a more personal relationship, where the professional behaviors were taken in accordance with the specificities of each case.

According to Klaus and Kennel (1993)[32], the family of the newborn in a NICU is going to live with high-tech equipment, mostly unknown, with unknown people, which ultimately sets up an environment that many consider to be scary. In addition, according to the authors, their family relationships and their beliefs are minimized due to the own service routine that prevents the full-time permanence of the parents next to the son. For Klaus and Kennel (1993)[32], the parents express different feelings during the internment period, which can range from guilt to concern, fear, anger and anxiety, which can be aggravated, for example, upon observing a painful procedure.

Through the reports it is possible to notice that mothers have appreciated when healthcare workers broke through the barriers of protocol relating to basic cares being performed only by the nursing staff, enabling conditions so that mother could get the baby on her lap and/or provide care for the children (changing diaper, giving milk through the probe, bathe, among others). These attitudes have contributed, according to reports, to reduce the suffering caused by the hospitalization of the baby in ICU.

Some people were human, and by the fact that they also happen to be, provided a better and more humane environment with little gestures but of individual initiative, as for example, set in

order the child when they arrive, be kind enough to offer to put them in my lap or not, free up some more time in the ICU, to be able to stay a little longer, talk, hear, put on a lacework (M1L6)

The permission for the mother's physical contact with the New Born was something cited as a positive factor which contributed to care humanization in the NICU.

[...] the nurse put V on my lap and this was something completely surprising for me because I didn't even know they could leave the isolation unit. (Laughs). (M4L519)

In addition, situations where healthcare professionals showed a closer relationship with the babies and mothers were valued.

So, there was this humanization part, there it was very human, very pleasant. Their bathing time was kind of fun, because it was the time they get out of bed and did something different. (M6L1134)

We cut hair in the ICU! (Laughs) I was the hair-cutter of the ICU! (Laughs) D. always had curly hair and then one day we decided to cut it and everyone liked it! A nurse said: ahhh let's pass the little machine?! And then she brought it, and she lent me the little machine. (M6L1140)

Even in the most difficult situations, there was the possibility for perception of humanized care, where M1 recounts the time when healthcare professionals respected the family's need to say good-bye to the baby and provided conditions for this farewell.

Then she cut off [...] of course, she did not turn off the respirator, but cut off serum, medicine [...] there was no more reason because none of this at that moment... take medicine [...] dying while taking medicine? And brought to the lap, right? Brought course with an oximeter[...] of course that with mechanical ventilation and so on… And then she got in my lap [...] the team was not required to be within the ICU room at that time [...] everybody got out [...] who was necessary stayed, who was not needed LEFT [...] It was an extremely respectful act... and we were saying goodbye… (M1L197)

Couto and Praça (2009)[33] warn on the need for strategies of promoting the link between professionals and caregivers to still occur in the hospital ambience so that this discharge process can be facilitated and becomes safe for both the premature newborn, and for the family. These situations are intrinsically linked to mother's autonomy in the hospital, required for the babies to have fit caregivers at home, after the discharge period.

In the report below, the need of the mother to participate in the baby care, is evident.

[…] and they always allowed this, I was going to change a diaper, sometimes in time to remove it I could stay a little with her in my lap, weigh the urine, be part of this kind of routine [...] push the milk through the probe, which was very important, because I took out the milk, taking it, every day [...] it was almost my way to help, right?, to be in some way her feed provider. (N4L549)

In all the above-mentioned reports, the professionals promoting individualized care, not just following protocols and yes observing the needs of each individual, contributed to strengthening the link between mother-baby, through physical approximation between both, and promoted the mother's training to take care of the baby after hospital discharge, through educational activities, such as teaching the basic care with the newborn (changing diaper, feeding, putting on the lap, bathing, among others).

FINAL CONSIDERATIONS

This research sought to situate the humanization process in the field of power relationships where it was possible to verify that the instance of symbolic violence is a worsening of dehumanization in hospitals under the perspective of mothers that are accompanying babies admitted to Neonatal ICUs.

In this way, it is possible to identify that the humanization process is going on, especially, by setting up less asymmetric power relations between the hospital staff and accompanying mothers. Although the understanding of humanization design is procedural, this is a path that needs to be constantly enhanced, including in the National Humanization Policy, deriving from concepts and provisions that aim at the reorganization of the work processes in health, proposing changes in social relationships, involving health workers and users, insofar as it proposes changes in the ways to provide services to the population, through care humanization. According to Santos-Filho (2007)[34], NHP's proposal coincides with SUS very principles, emphasizing the need to "ensure comprehensive care for the population and strategies to extend the condition of citizenship and rights of the people". In this way, it is undeniable to confirm the advance that such a policy represented for society. However, through the reports of the interviewees, it was noted that various NHP's guidelines are not effectuated in hospital practice, considering that all subcategories were built up based on official documents of the National Humanization Policy and the research corpus.

Most reports concerning humanizing factors made mention to individualized care. Mothers appreciated situations where the case of their babies was treated according to their specific characteristics, such as: let cut the hair (in the NICU) of a baby who was hospitalized for many months; let the parents say goodbye to a baby in a terminal state, among others. This evidence confirms with studies that have shown that the patients need a care focused on their specific characteristics [22,27-28].

In relation to dehumanizing factors, in addition to the situations regarding the lack of physical structure in the hospital, the disrespect to the rights of the child called attention, with regard to article 12 of the Child and Adolescent Statute (1990)[29], which states that "the hospitals must provide conditions for full-time residency of a parent or guardian, in cases of child or adolescent hospitalization". We can observe that the failure to respect the rights of the child, in this case, is linked to conditions of physical hospital-related structure. By the fact of their babies needing care

in intensive care units, mothers are subject to the rules and conducts of the professionals, giving legitimacy to the power they exercised. Therefore, even being conscientious on their rights, they are subject to situations where they are not accomplished.

The hospitalization of neonates in NICU deconstructs the idealized image of the child and family identity. The parents, unable to take the child home, are forced to modify their plans to experience their history next to the new family member. Mother's experience is intrinsically linked to the need for building up motherhood. Through these reports, it was possible to notice that the mothers show conflicting feelings in relation to the baby's care; at the same time, they are feeling fear to make a wrong procedure and cause damage to the child, they want autonomy to provide the cares. Being able to touch the baby, cuddle, change diaper, breastfeed or pass the milk through the probe are concrete care experiences and, therefore, important for the mother-baby bond. Thus, it is clear that NICU environment must allow for and encourage family participation in providing cares to the baby. Not only fulfilling NHP's rules, for open visitation and extended visitation, and yes on creating an environment where the family does not feel being secondary in the baby's life. So, more dialogical relationships between health users-professionals, understanding the users as able to exercise their autonomy and their protagonist capacity, not only contribute to sharing responsibility for healthcare, but also for greater balance in relations of power in the hospital.

This study was limited to understanding the experience of a single member of the family – the mothers of babies admitted to NICU, however, there is a need for researches focusing on the experience of other family members, in order to analyze the interaction between the different social actors and the baby hospitalized in a NICU.

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